Accessing NASA Astronaut Medical and Research Data

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2017 TCC EVA Technology Workshop

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Data Accessibility

- Until ~2010, the only astronaut data available to researchers was de-identified or grouped data archived within the Life Sciences Data Archive (LSDA)

- We have been developing processes to enable and streamline the release of individual data from both research and medical archives

Prospective Research

- NASA's Human Research Program (HRP) has well-established data sharing processes for purely prospective data
  - Flight research facilitated by ISS Medical Project (ISSMP):
    - Integrates informed consent briefings with crew
    - Develops Increment-specific Data Sharing Plans
      - Exchange of research data among PIs with attention to protecting rights of first publication
      - Documents medical data to be released from LSAH for research studies
  - Flight Analog research facilitated by Flight Analogs Project (FAP)
    - Analogs: such as Bed Rest Study at UTMB, and NEEMO
    - Similar, campaign-specific Data Sharing Plans for the exchange of research data
    - Bed rest data available includes Standard Measures data

Retrospective Research via Life Sciences Data Repositories

LSDA
Life Sciences Data Archive

Research Data

- Active archive of HRP research
- Historical flight data 1961-Shuttle
- Ground-based and flight analog data
- Human, animal and plant data
- Animal biospecimens available for research

LSAH
Lifetime Surveillance of Astronaut Health

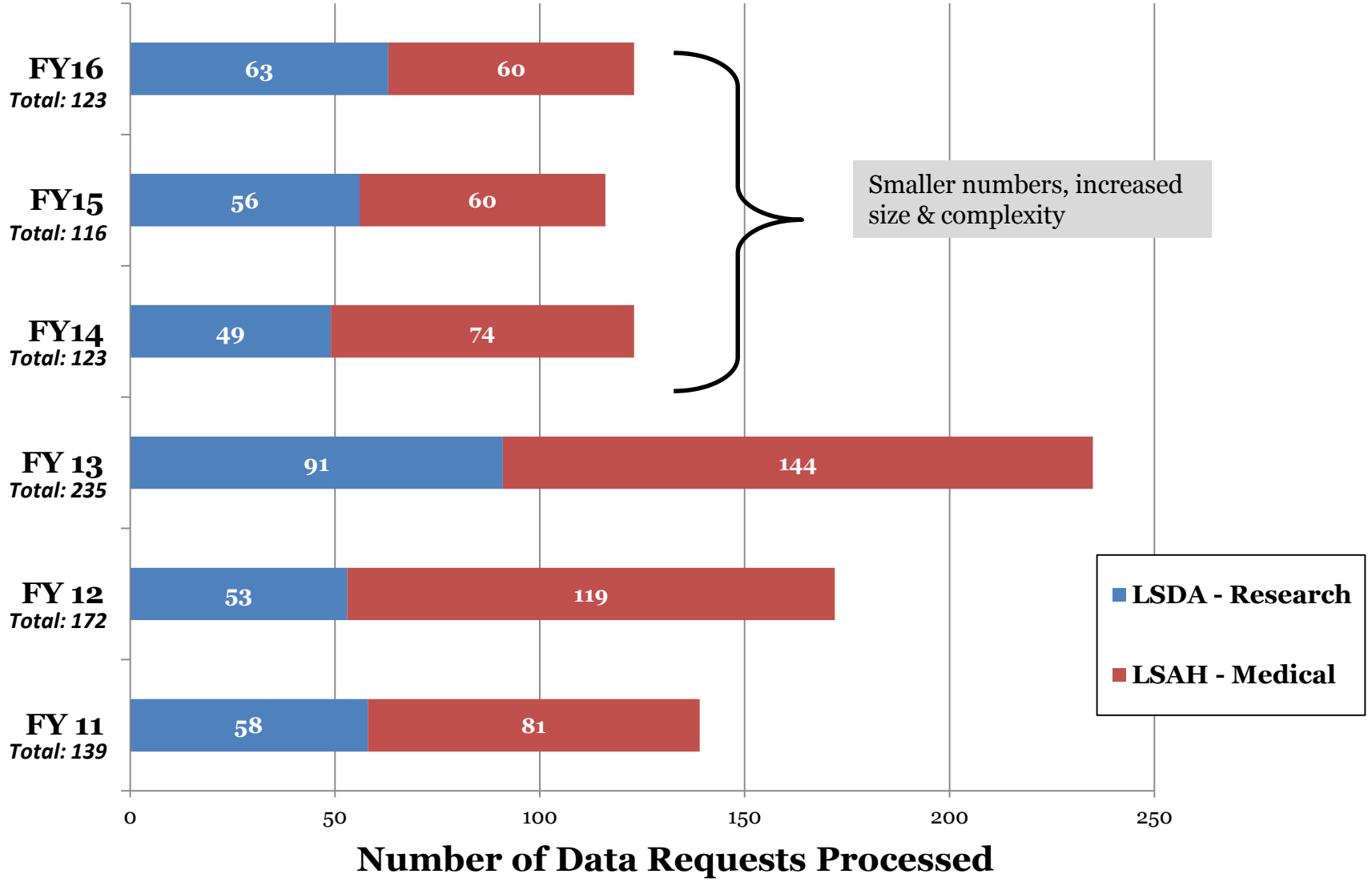
Medical Data

- Data for all astronauts selected to the corps beginning in 1959, including retirees who return for annual exams
- Includes ground & flight medical exam & mission health data (e.g., MRID/MEDB, vehicle, environment data)

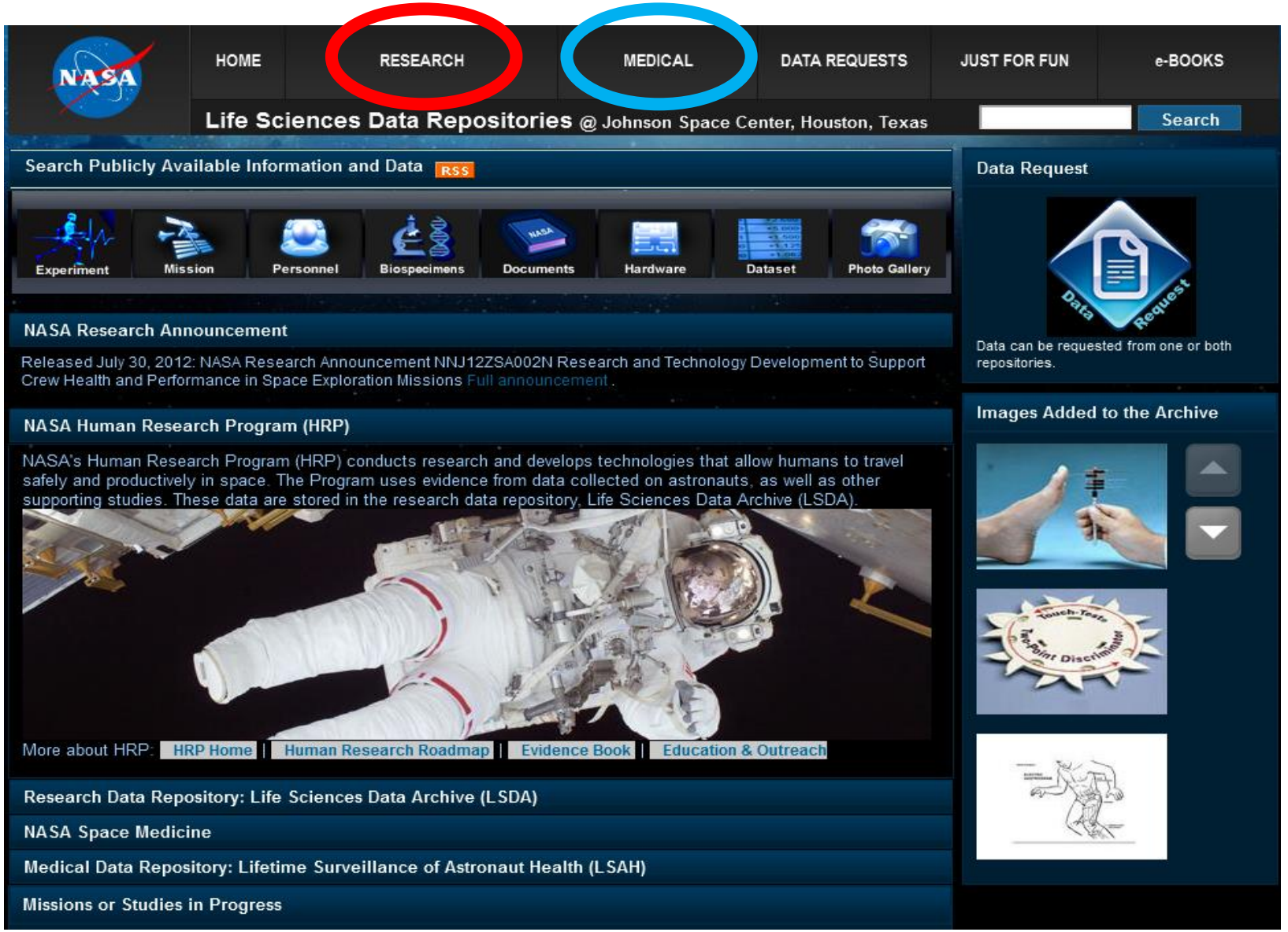
Future Plans

- Human Performance Database
- EVA Suit Exposure Tracking

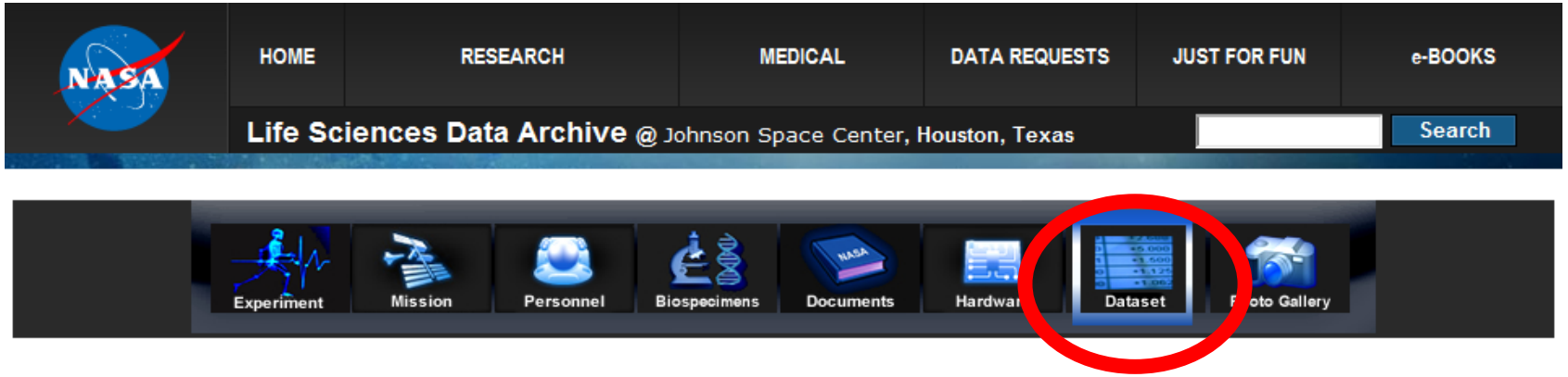
Astronaut Data: Number of Requests by Fiscal Year

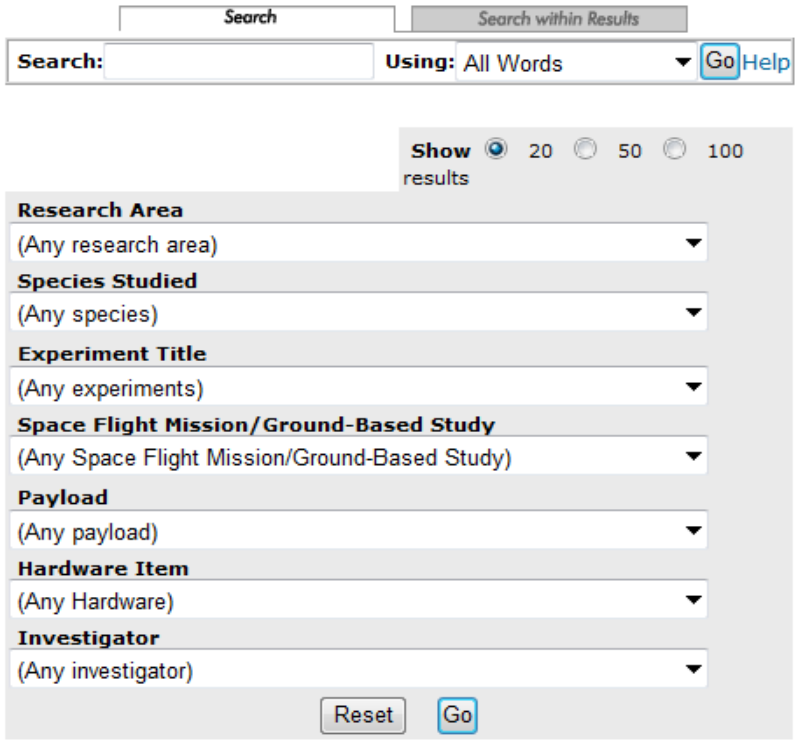


Information on Public Website: https://lsda.jsc.nasa.gov



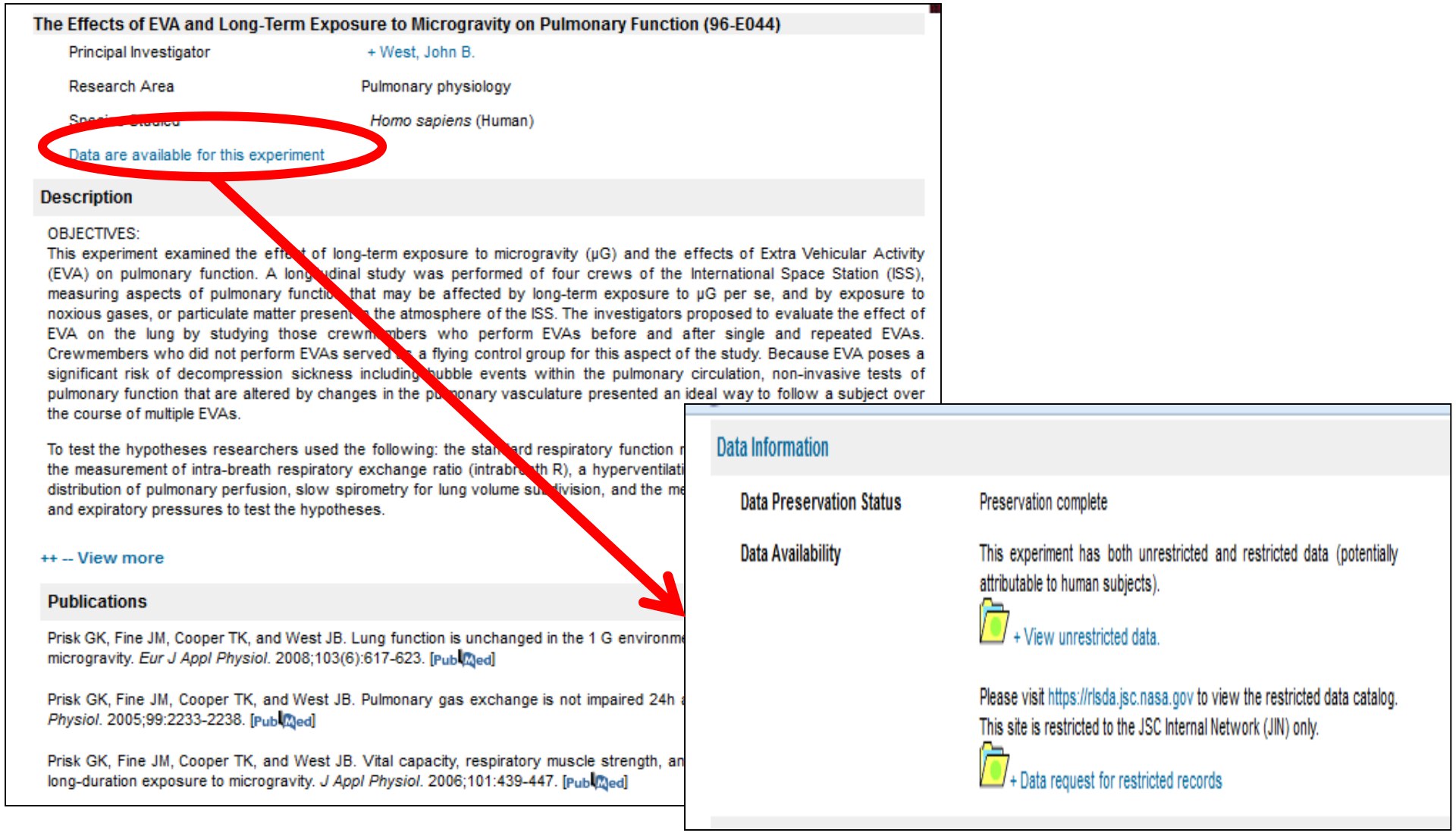
Searching for Specific LSDA (Research) Data





Search by keyword or other parameters through the 'Dataset' portal

Experiment-Specific Information



The Effects of EVA and Long-Term Exposure to Microgravity on Pulmonary Function (96-E044)

Principal Investigator + West, John B.

Research Area Pulmonary physiology

Species Studied *Homo sapiens* (Human)

Data are available for this experiment

Description

OBJECTIVES:
This experiment examined the effect of long-term exposure to microgravity (µG) and the effects of Extra Vehicular Activity (EVA) on pulmonary function. A longitudinal study was performed of four crews of the International Space Station (ISS), measuring aspects of pulmonary function that may be affected by long-term exposure to µG per se, and by exposure to noxious gases, or particulate matter present in the atmosphere of the ISS. The investigators proposed to evaluate the effect of EVA on the lung by studying those crewmembers who perform EVAs before and after single and repeated EVAs. Crewmembers who did not perform EVAs served as a flying control group for this aspect of the study. Because EVA poses a significant risk of decompression sickness including bubble events within the pulmonary circulation, non-invasive tests of pulmonary function that are altered by changes in the pulmonary vasculature presented an ideal way to follow a subject over the course of multiple EVAs.

To test the hypotheses researchers used the following: the standard respiratory function r
the measurement of intra-breath respiratory exchange ratio (intrabreath R), a hyperventilati
distribution of pulmonary perfusion, slow spirometry for lung volume subdivision, and the me
and expiratory pressures to test the hypotheses.

++ -- View more

Publications

Prisk GK, Fine JM, Cooper TK, and West JB. Lung function is unchanged in the 1 G environme
microgravity. *Eur J Appl Physiol*. 2008;103(6):617-623. [PubMed]

Prisk GK, Fine JM, Cooper TK, and West JB. Pulmonary gas exchange is not impaired 24h a
Physiol. 2005;99:2233-2238. [PubMed]

Prisk GK, Fine JM, Cooper TK, and West JB. Vital capacity, respiratory muscle strength, an
long-duration exposure to microgravity. *J Appl Physiol*. 2006;101:439-447. [PubMed]

Data Information

Data Preservation Status	Preservation complete
Data Availability	This experiment has both unrestricted and restricted data (potentially attributable to human subjects).

+ View unrestricted data.

Please visit https://rlsda.jsc.nasa.gov to view the restricted data catalog.
This site is restricted to the JSC Internal Network (JIN) only.

+ Data request for restricted records

Medical Information on Public Website: https://lsda.jsc.nasa.gov

Medical Operations

The Space Medicine Division mission is to optimize the health, fitness, and well being of flight crews.

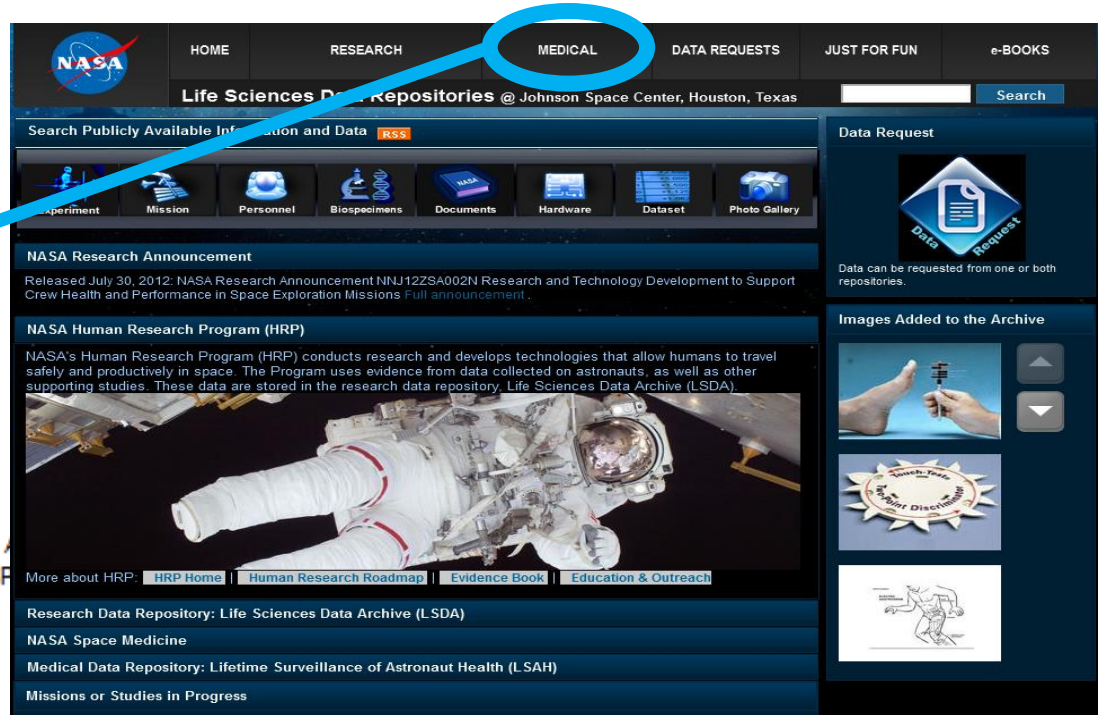
Astronaut medical data are collected per requirements detailed in t + Medical Requirements Integration Documents (IID's).
Data collected during these medical tests are generally housed in the Li Surveillance of Astronaut Hea (LSAH) repository. These test protocols are divided into areas as shown below. Each MRID will give an indication of the type of testing performed as well as the frequency of such tests.

FIND IT @ LSDA Search

Click on an category image for relevant MRID information:

- Behavioral Health and Performance
- Bone, Muscle, Exercise
- Cardiovascular
- Environmental Health
- Extravehicular Activity (EVA)
- Immunology
- Neurology
- Nutrition
- Radiation
- Therapeutics and Clinical Care
- View All Medical Requirements

Note: The Medical Requirements Integration Documents (MRIDs) reflect the Medical Requirements documented in the A Requirements Document (AMERD), JSC 24834, the ISS Medical Operations Requirements Document (ISS MORD), SSP Medical Operations Requirements Document (MORD) JSC 13956.



LSAH Publicly Available Information

Medical Requirements

- Documents outline medical tests performed on ISS crew
- Click blue text to see testing details to help determine the data you need

All Medical Requirements

Discipline	MRID#	MEDB#	Medical Requirement Title
Behavioral Health and Performance		MEDB 7.7	+ Behavioral Observation of Training
Behavioral Health and Performance		MEDB 7.4	+ Mood Assessment
Behavioral Health and Performance		MEDB 7.1	+ Preflight Behavioral Health Status Check
Behavioral Health and Performance	MR027L	MEDB 7.5	+ Post-flight Psychiatric/Psychological Evaluation
Behavioral Health and Performance	MR027L	MEDB 7.2	+ Preflight Evaluations
Behavioral Health and Performance	MR031L		+ Private Psychological Conferences (PPCs)
Behavioral Health and Performance	MR032L		+ ISS Private Family Conferences (PFCs)
Behavioral Health and Performance	MR032S		+ Private Family Conferences (PFCs) for Shuttle Crews
Behavioral Health and Performance	MR085L	MEDB 7.6	+ Neurocognitive Assessment
Bone, Muscle, Exercise		MEDB 5.4	+ Calf Volume Measurement
Bone, Muscle, Exercise		MEDB 5.1	+ Functional Fitness Assessment
Bone, Muscle, Exercise	MR006L		+ Exercise Treadmill Test
Bone, Muscle, Exercise	MR019L		+ Heart Rate Monitoring

LSAH Newsletters

- Published periodically to keep participants informed on the program's findings


National Aeronautics and Space Administration

THE LIFETIME SURVEILLANCE OF ASTRONAUT HEALTH

Newsletter

Spring 2012 Volume 10, Issue 1

Editor's Note: This spring's newsletter focuses on NASA's rapidly evolving interest in visual acuity changes associated with microgravity environments. There are currently a variety of theories and studies focusing on concerns recently brought to light, which we outline for you here. Lifetime Surveillance of Astronaut Health (LSAH) staff have spent countless hours on these investigations as part of our occupational surveillance program, and will continue to work towards better understanding and mitigating space flight health risks.

What's New in Space Medicine – Can you say "VIIP"?

By: William Tarver, MD

NASA has documented that several long duration astronauts have experienced in-flight and postflight changes in vision and eye anatomy, including degraded distant and near vision, swelling of the back of the eye (optic disc and retina), and changes in the shape of the globe (flattening of the back of the eye). In a few astronauts we have also documented postflight increases in the pressure of the fluid that surrounds the brain and spinal cord. This is referred to as increased intracranial pressure (ICP). The functional and anatomical changes have varied in severity and duration. In the postflight time period, some individuals return to preflight visual acuity, while others have

the closest terrestrial clinical model for us to compare against, the NASA documented clinical entity remains a unique spaceflight associated problem.

To address this unique problem, the Space Life Sciences Directorate (SLSD) at NASA Johnson Space Center has assembled a Visual Impairment Intracranial Pressure (VIIP) project team to address both operational capabilities and the development of a research plan. The operations arm of the project is addressing the implementation of medical requirements, and the immediate clinical needs of the NASA flight surgeons, such as enhanced diagnostic and treatment capabilities to respond to in-flight and postflight di-

National Aeronautics and Space Administration

THE LIFETIME SURVEILLANCE OF ASTRONAUT HEALTH

Newsletter

Fall 2012 Volume 10, Issue 2

Editor's Note: This edition of the newsletter focuses on various programs and services provided by and in conjunction with the Lifetime Surveillance of Astronaut Health (LSAH). We feel it is important to keep you up-to-date with current program offerings, data issues, and upcoming organizational changes. Additionally, please see the last page for a slightly truncated list of publications that have resulted from astronaut data provided by LSAH.

Individual Exposure Profiles: Documenting and Evaluating the Risks to Astronaut Health

By: Jessica Garcia, MPH

This spring, the Lifetime Surveillance of Astronaut Health (LSAH) began a project to compile and verify astronauts' occupational exposures to hazards such as intense noise, injuries, and radiation. These Individual Exposure Profiles (IEPs) will document exposures over each astronaut's lifetime, with specific emphasis on those hazards unique to working at NASA. A more individualized health care protocol can then be created for each astronaut based on their specific risks. The project was conceived in an attempt to pull together hazard exposure and related outcome information from a variety of sources into one concise document for each astronaut. Information is gathered from sources such as the electronic medical record (EMR), the Shuttle Data Archive, the LSAH data base, the Life Sciences Data Archive (LSDA), mission and training documents, and biographical data. These data are put into a summary form that guides a one-time in-person interview, which is conducted by an epidemiologist at the time of the annual exam. This conference gives each astronaut a chance to verify the facts and add missing details.

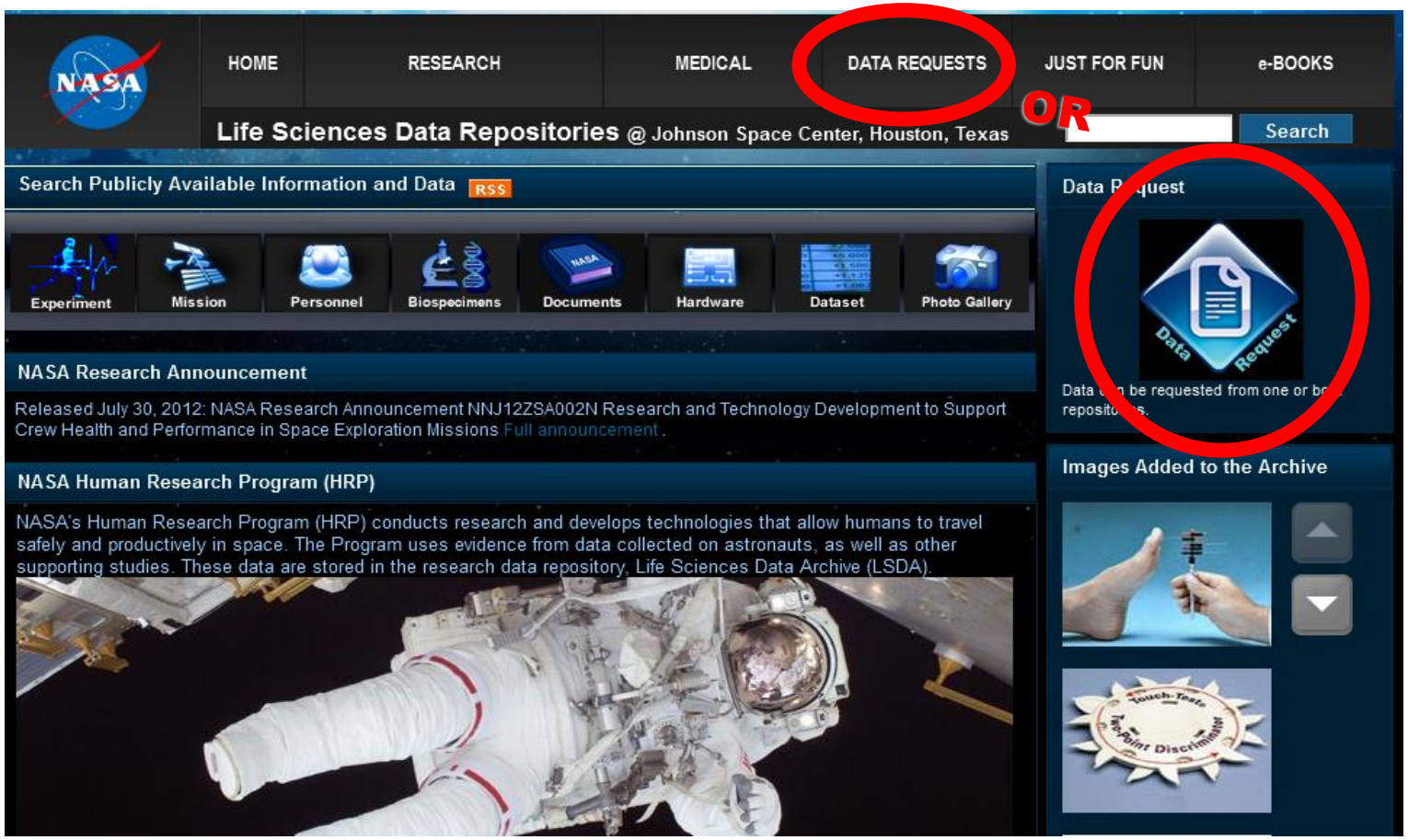
LSAH is also interested in pre- and post-NASA exposures such as military service, previous work or childhood exposures, and current hobbies. Some astronauts may wonder why there are questions about non-NASA-related experiences, but these exposures are what could be considered a baseline. Without a comprehensive understanding of the whole risk profile of an astronaut, we can't properly assess the risk of space flight to current and future crewmembers. Additionally, these IEPs may help guide future attempts to secure legislation for federal funding of retired astronauts' healthcare, which requires a thorough understanding of the lifetime risks to astronaut health.

Currently, the focus is on completing IEPs for retired astronauts returning to JSC for their annual physicals, especially those who do not reside in the Houston metro area. Contact is most often made through email a week or two prior to the exam, and the interview generally occurs immediately following the physical in the Flight Medicine Clinic offices. While participation is not mandatory, LSAH hopes every astronaut will be enthusiastic to take part and help us better tailor our exams and, in the long run, ensure the health of the entire astronaut corps.

For past newsletters, please visit the LSAH website

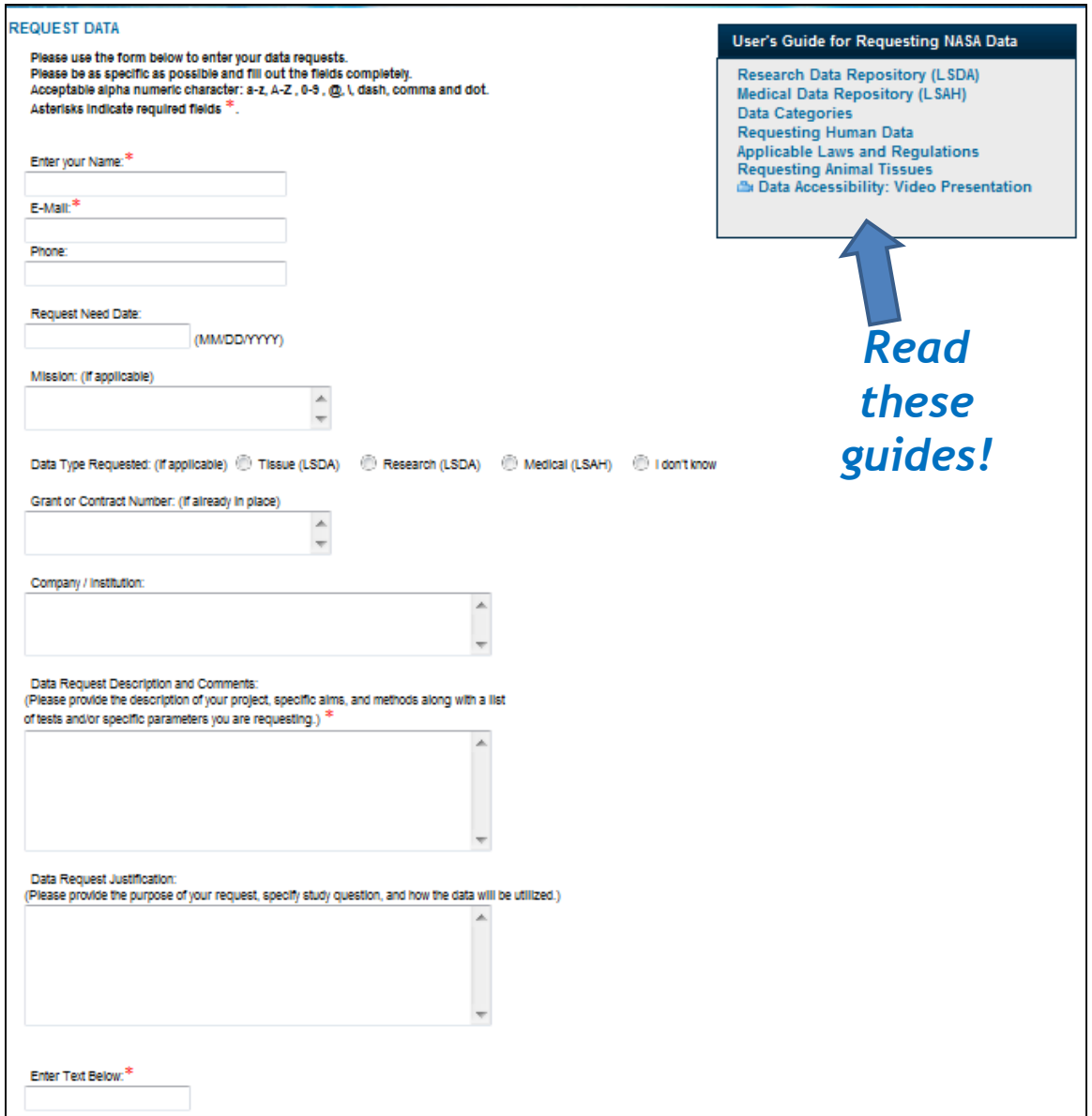
Requesting Data Not Available on Website

- Individual astronaut data are not downloadable
  - Potentially attributable to an individual subject
  - Protected by the Privacy Act
- HOWEVER, individual data can be requested for research, medical and operational purposes
  - Currently, medical data are available for US crewmembers only
  - Usually requires funded, peer-reviewed study, IRB protocol, crew consent



https://lsda.jsc.nasa.gov

Data Request Form



REQUEST DATA

Please use the form below to enter your data requests.
Please be as specific as possible and fill out the fields completely.
Acceptable alpha numeric character: a-z, A-Z , 0-9 , @, \, dash, comma and dot.
Asterisks indicate required fields *.

Enter your Name:*

E-Mail:*

Phone:

Request Need Date:
(MM/DD/YYYY)

Mission: (if applicable)

Data Type Requested: (if applicable) Tissue (LSDA) Research (LSDA) Medical (LSAH) I don't know

Grant or Contract Number: (if already in place)

Company / Institution:

Data Request Description and Comments:
(Please provide the description of your project, specific aims, and methods along with a list of tests and/or specific parameters you are requesting.) *

Data Request Justification:
(Please provide the purpose of your request, specify study question, and how the data will be utilized.)

Enter Text Below:*

User's Guide for Requesting NASA Data

- Research Data Repository (LSDA)
- Medical Data Repository (LSAH)
- Data Categories
- Requesting Human Data
- Applicable Laws and Regulations
- Requesting Animal Tissues
- Data Accessibility: Video Presentation

Read these guides!

Your request must include:

- Contact Information
- Date when data are required (>3 months)
- Grant, NRA#, or current project that data will support
- Institution
- "Data Request Description" – i.e., what data you are requesting? Be detailed
- "Data Request Justification" – i.e., why do you need this data? If requesting individual data, why can't de-identified or grouped data be used?
- More detail, the faster your request can be scoped

Data Request Timeline

- **The timeline for any single data request (DR) depends on many factors, and no two are the same**
- **Easiest/fastest:** Demographic data or incidence of a particular issue on small number of ISS crew (US only) and single aim
- **Hardest/slowest:** Large number of variables or multiple types of data (e.g., imaging, video, textual) and a large number of crew, mixed ISS and previous programs, multiple aims; needing International Partner crew; any dataset with missing data that need to be retrieved (e.g., EVA injury, medications, exercise) or where policy/data sharing hasn't been determined (e.g., any genetic information)

EVA Data Request Considerations

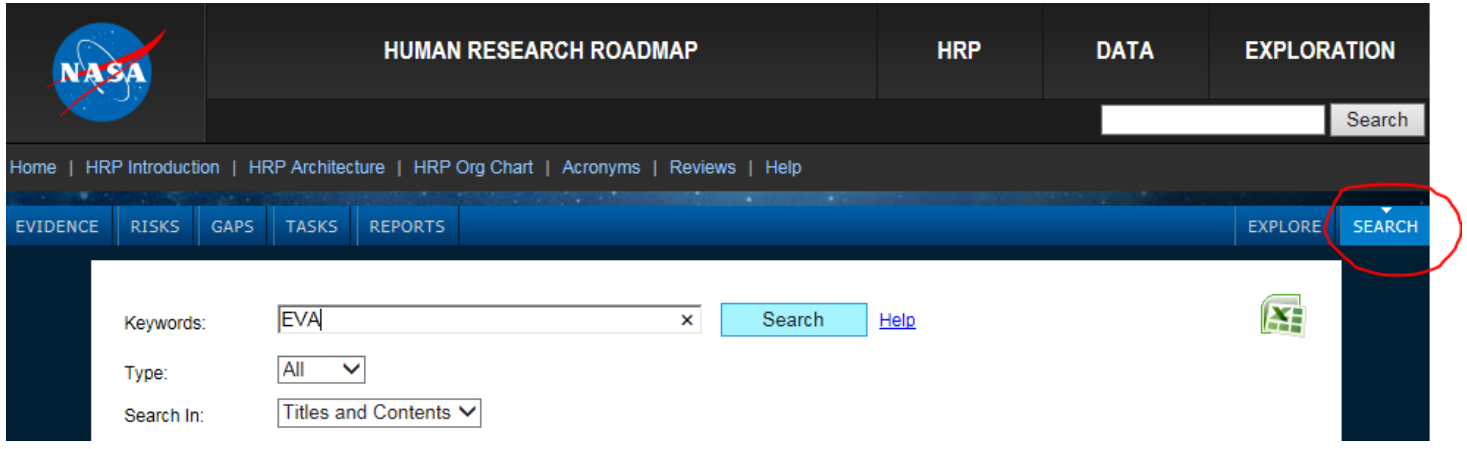
- Most NASA medical data was collected for clinical care purposes and may not include parameters required for your research
  - Diagnoses may not comply with research definitions because focus is on clinical care treatment
  - Testing is conducted to diagnose and treat; may not meet research standards in terms of parameters collected, consistency of schedule or constraints
- Suggestions for Data Mining Study Development
  - Consult with LSAH personnel early during study development
    - We can assist you in understanding exactly what data is available, what the necessary lead time is for pulling/cleaning/processing, and other potential issues
    - Data we have MAY be available for re-interpretation with proper permissions
  - If your study has an inflight component, consult with HRP, ISSMP (ISS Medical Project) personnel for special time, hardware, other requirements

EVA Data Availability

- EVA Suit Exposure Tracker (SET) – LSAH has compiled all available US astronaut EVA training runs into one database.
  - Over 12,000 training runs from neutral buoyancy training for 232 astronauts
  - Data quality is best after 1985; earlier records inconsistent
  - NASA Technical Memo describing the dataset just published:
    - https://ston.jsc.nasa.gov/collections/TRS/listfiles.cgi?DOC=TM-2017-219291
  - Need approval from the NASA EVA community to release datasets to internal or external requesters (anticipated in FY18)
  - Suit fit runs and non-EMU training records were excluded
  - Data for some runs has not been location although photographic evidence exists (training partner data was used in some cases)
  - These data were compiled with assistance from Randall McDaniel, Kevin B. Thomas, Marc Ciupitu & GCTC staff

EVA Data Availability (cont.)

- Crew Comments Database -
  - Compilation of over 70,000 comments from post-mission debriefings on a variety of topics
  - Description of data available in the crew comments database published as NASA Technical Presentation
  - https://ntrs.nasa.gov/archive/nasa/casi.ntrs.nasa.gov/20160011585.pdf
- Human Research Program Evidence Books
  - https://humanresearchroadmap.nasa.gov/evidence/



Examples of EVA Data Requests Filled in the Past

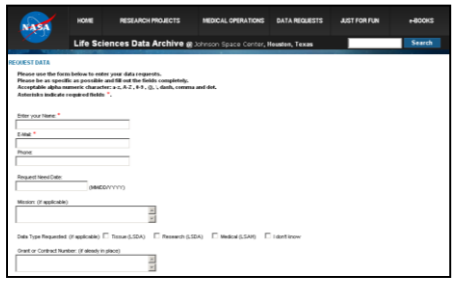
- Hand Injury / Glove sizing
- Suit sizing and anthropometry*
- EVA Hypoxia and Sleep
- Shoulder, Elbow Injury / Suit Trauma (typically upper body)
- Metabolic data from graded exercise tests, EVAs where available
- Infection rates in EVA crew
- Medical data from annual exams, flight-specific medical requirements
- Vehicle and crew-worn environmental and acoustic data (O2, CO2, radiation, etc.)
- Medication use
- Clinical blood or urine, nutritional parameters

- **Limited anthropometry, suit sizing data available; other sources may need to approve, collaborate with dataset*

Questions?

Backup Slides

Data Request Fulfillment



Automated email to requester

Data Request Clearinghouse

Obtain more info

Data Availability Check

LSAH Data

LSDA Data

Confirm with Requester

Request approved

Request Approval Process:

- ✓ Request purpose?
- ✓ Merit established?
- ✓ Attributable data?
- ✓ IRB review required?
- ✓ Consent necessary?

Request not approved

Notify requester; modify request

Requester notified of anticipated schedule; signs data use agreement if required

Retrieve missing data

Assimilate Data from Various Sources

Mission Medical Records
LSDA Archive
Training Records
Clinic/LSAH Records
Vehicle Environmental Data
Biospecimen Data
Research Study/Laboratory Data
Questionnaires/Surveys

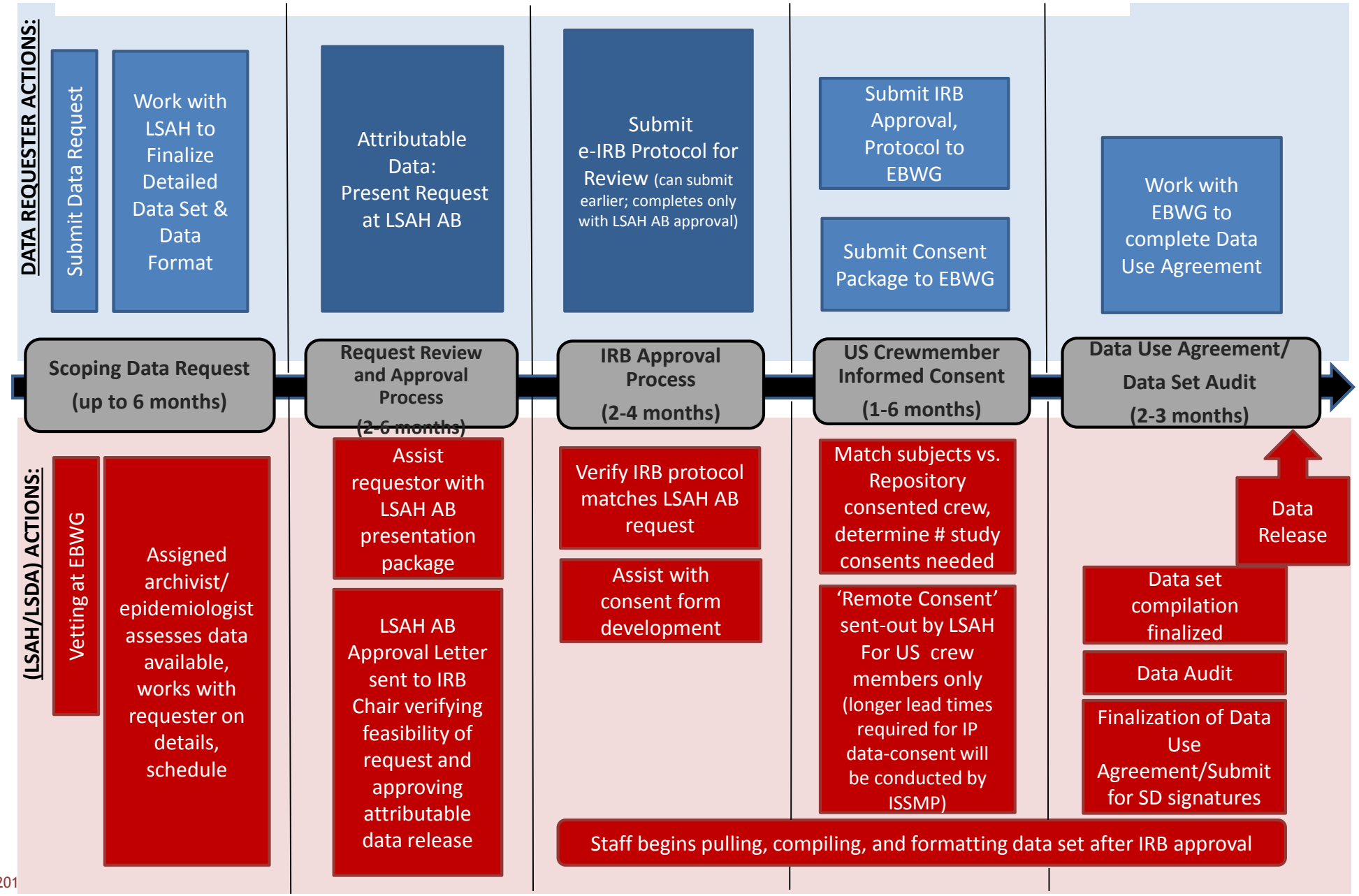
Perform Data Quality Assurance

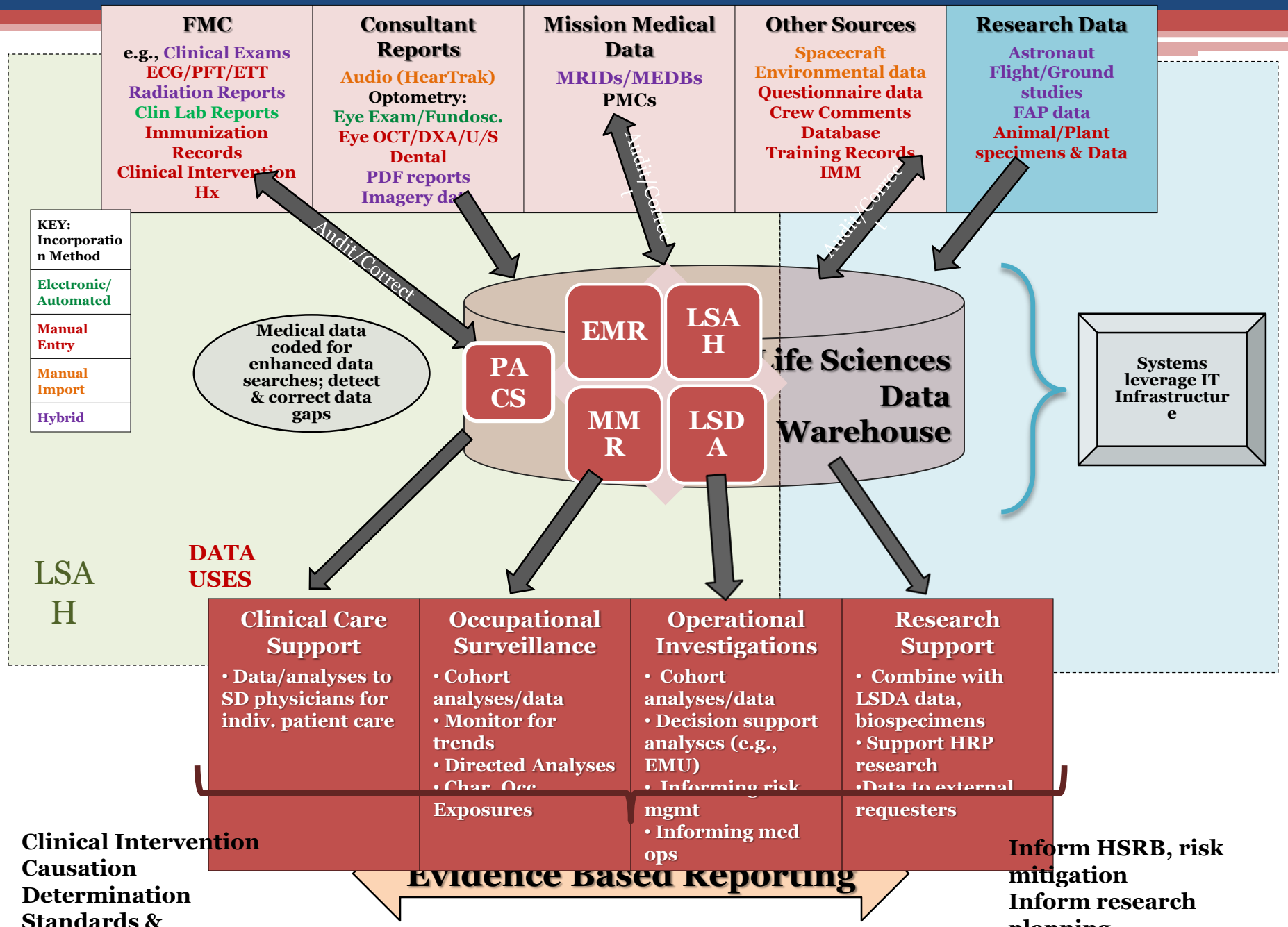
Consent Forms Complete (if req'd)

Data sent to Requester

Key Elements of Retrospective ATTRIBUTABLE Data Request Process

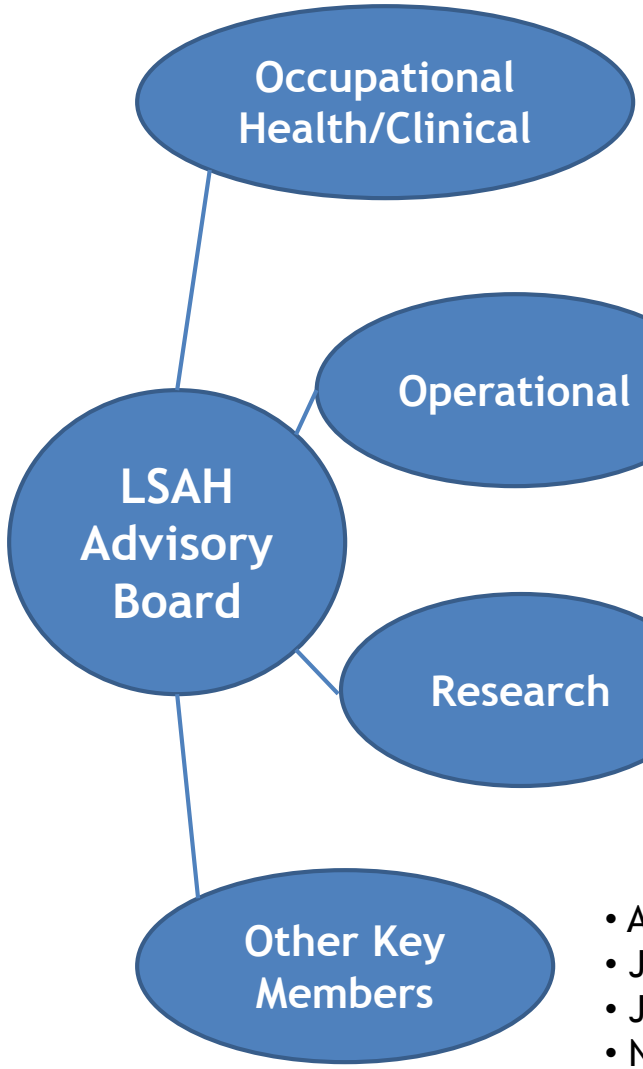
(duration of each step depends on size, complexity of data set)




FMC
e.g., Clinical Exams
ECG/PFT/ETT
Radiation Reports
Clin Lab Reports
Immunization Records
Clinical Intervention Hx
Consultant Reports
Audio (HearTrak)
Optometry:
Eye Exam/Fundosc.
Eye OCT/DXA/U/S
Dental
PDF reports
Imagery da
Mission Medical Data
MRIDs/MEDBs
PMCs
Other Sources
Spacecraft
Environmental data
Questionnaire data
Crew Comments
Database
Training Records
IMM
Research Data
Astronaut Flight/Ground studies
FAP data
Animal/Plant specimens & Data
KEY: Incorporation Method
Electronic/ Automated
Manual Entry
Manual Import
Hybrid
Audit/Correct
Audit/Correct
Audit/Correct
Medical data coded for enhanced data searches; detect & correct data gaps
PACS
EMR
LSAH
MMR
LSDA
ife Sciences Data Warehouse
Systems leverage IT Infrastructure
LSAH
DATA USES
Clinical Care Support
• Data/analyses to SD physicians for indiv. patient care
Occupational Surveillance
• Cohort analyses/data
• Monitor for trends
• Directed Analyses
• Char. Occ Exposures
Operational Investigations
• Cohort analyses/data
• Decision support analyses (e.g., EMU)
• Informing risk mgmt
• Informing med ops
Research Support
• Combine with LSDA data, biospecimens
• Support HRP research
•Data to external requesters
Evidence Based Reporting
Clinical Intervention Causation Determination Standards & Requirements
Inform HSRB, risk mitigation
Inform research planning
Inform ops, DRM

LSAH Advisory Board

Chair: Chief, Space & Clinical Operations Division or designee



- Occupational Health Branch Chief
- Medical Operations Group Lead
- JSC Clinic Medical Director
- Crew Health & Safety Physician Liaison
- LSAH Program Manager

- Information Systems Architecture Branch Chief
- ISSMP Representative*

- HRP Chief Scientist
- Biomedical Research & Environmental Systems Division Chief
- Human Systems Engineering & Development Division Chief
- LSDA Manager
- BDRA Project Manager*
- International Science Office Chief

- Astronaut Office Physician Representative
- JSC Legal Office Representative
- JSC Institutional Review Board Chair
- NSBRI Representative (physician)

*Dual assignment

Board Purpose

This board reviews:

- All requests for attributable data (except clinical care)
- Other requests forwarded to the board by EBWG
- Requests where NASA policy is not yet determined

Meets 4th Tuesday of each month

Evidence Base Working Group Membership

Group Purpose

EBWG is the clearinghouse for all incoming data requests

Releases public or un-attributable data

Facilitates data requests through approval processes to release

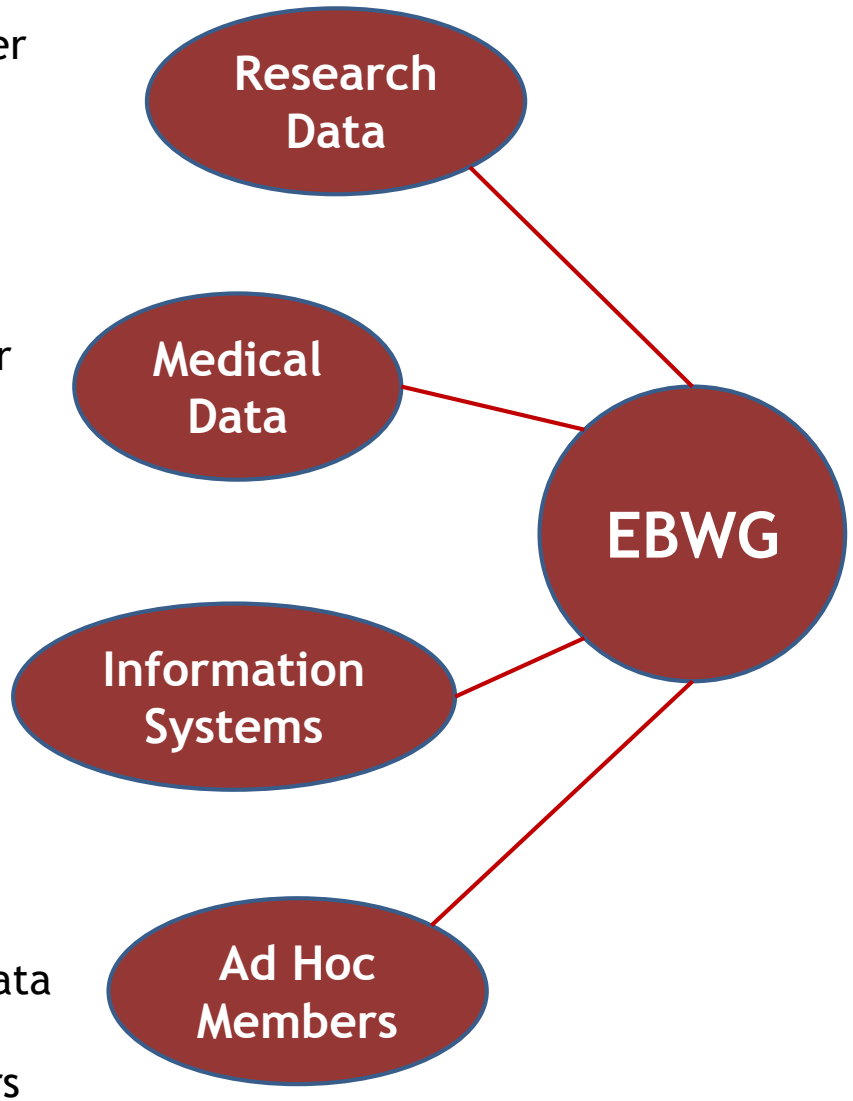
Meets every other Monday

- LSDA NASA Manager
- LSDA Archivists

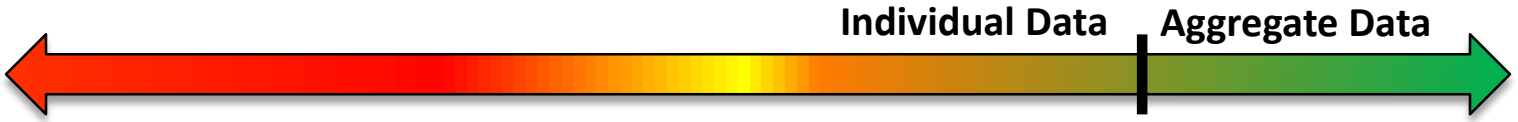
- LSAH NASA Manager
- Epidemiology Manager
- LSAH Epidemiologists
- BDRA Epidemiologist

- Information Systems Architecture Branch Chief
- *Space Medicine, LSDA IT staff (consultants)*

FUTURE?
- Human Performance Data Base staff
- Other archive managers



Data Attributability Continuum



Attributable: e.g.,'DSO' Codes

Describes variables from an individual such that the recipient of the data set can easily ascertain the identity of the individual, such as to match characteristics across more than 1 data set. Although attributable, individual names are never provided with data set.

(Consent Required)

Coded: Random Codes

Describes variables from an individual, but that individual is assigned a code such that the recipient of the data set cannot ascertain the identity of the individual. The sender of the data maintains the only available key to connect codes to individual subjects.

Grouped/ Pooled

Data variables from a group of individuals are reported together, thereby removing individually identifiable information.